

Caregiving for aging parents

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I will again be called upon to help care for aging parents, and I will be the aging parent who will want my adult children to help care for me.

COMPILERS' COMMENTS

I left home in the fall of 1963 when I enrolled in Goshen College's School of Nursing. It was a four hour car drive from my childhood home in rural Rantoul, Illinois. I got married one week after I graduated from college in June 1967 and moved farther from home to Pennsylvania. I was young, adventurous, and naive. I believed my husband when he said he was not planning to live in Pennsylvania after he graduated from Hahnemann Medical School. But one path led to another until 31 years later, we are settled in Mount Joy, Pennsylvania. We live on the farm where Ken was born and raised.

Recently we were in the Midwest to visit our youngest daughter and her husband. Visiting Kansas and then rural Missouri reminded me of home. I wonder how my mother coped with her daughter 700 miles away. It was difficult for me 11 years ago when my mother suffered several strokes and needed care. I was busy with a house, a spouse, three children, and a new job. I remember how guilty I felt at that time for having moved so far away from home. I should have anticipated that my parents would age and need help from a dutiful daughter at some time in their lives. I felt like a piece of meat squeezed between two slices of bread. Being the oldest daughter, I felt like a bad girl even though I regularly kept in touch with my sister and dad by phone. I traveled to Illinois a couple of weeks before my mother's death. Even though I was able to assist in bringing her home from the hospital and help provide care for her during the last four days of her life, I felt I had not done enough.

I wonder what it will be like as Ken and I continue to age. Two of our three married children live out of state. Who will care for me? What if I outlive my spouse? At some time in the future, my adult children will likely be challenged with me. They may have to figure out how to fit my needs into their busy lives. They may feel guilty for being so far away when I am old and in need of care and support. I know the tension and guilt of living miles away from my 85-year-old father, who is living



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Karin Gingrich Weaver lives in Lancaster, Pennsylvania with her husband Curt and cat Jinga. She works as a social worker in a continuing care retirement community and is in her last semester of graduate studies in social work.

We have beautiful retirement communities, personal care homes, and yes, even beautiful nursing homes for older adults, but they lack the opportunity for inter-generational relationships.

with COPD and a heart condition. I think of Ken's aging parents who live across the road from us and are still quite independent. Will I have the energy to help care for them when that time comes? I am freer now in some ways than when my mother needed care. But I now have grandchildren, a job, and responsibilities at church. I still have the house and the spouse.

Who knows what the next years will bring as I continue to age and as our parents continue to grow older. Of one thing I am sure. We will care for each other. I will again be called upon to help care for aging parents, and I will be the aging parent who will want my adult children to help care for me. These persons are family, and we will help each other as we are able, no matter where we live.

—Pamela Brubaker, co-compiler

There have always been challenges to aging. The losses of friends and family, physical health, and the ability to do some of the things that were once possible are many. Aging in the 21st century hasn't gotten any easier. Instead we have additional challenges that can make it more complicated. Families are scattered, schedules are full, we live longer and have access to ever-improving medical technology, and our society tends to age-segregate. These complications are not inherently bad, but they can make caregiving more difficult for families.

The MCC Committees on Women's Concerns believe that Jesus Christ teaches equality of all persons. By sharing information and ideas, the committees strive to promote new relationships and corresponding supporting structures through which women and men can grow toward wholeness and mutuality. Articles and views presented in REPORT do not necessarily reflect official positions of the Committees on Women's Concerns.

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The advances in medicine are expensive and may add quantity without enhancing quality of life. Adult children are finding themselves part of the sandwich generation with primary responsibility for the care of young children and aging parents. While options for women are increasing in the work force, the expectation that women do the bulk of the caregiving for children and elders remains much the same. We have beautiful retirement communities, personal care homes, and yes, even beautiful nursing homes for older adults, but they lack the opportunity for inter-generational relationships. The tendency to keep the generations separate means children lose out on opportunities to learn from the wisdom of the aged and the elderly get old before their time. The decisions that have to be made as a parent's health and/or physical ability declines are many and support to assist with decision-making can, at times, be too little. As the population ages, the number of children involved in the care of their parents will increase. Maybe through sharing our stories, we will all be better prepared for what may lie ahead.

The individuals who have graciously offered to share their personal stories and professional knowledge in this issue of *Women's Concerns Report* know well the complications and challenges of caring for aging parents. From the difficulty of arranging respite for a family vacation to working through the decision to allow a parent to die at home, the stories within share a variety of experiences. They are all different, yet in many ways the same. Grappling with guilt and resentment while seeing glimpses of beauty and sharing moments to be cherished, the authors communicate the contradictions and conflicts that they have had to face as they care for those who once cared for them.

—Karin Gingrich Weaver, co-compiler

I'm a young woman, 33 years old, and still consider my parents to be smarter and wiser than I am. I still believe that they will have the perfect advice whenever I need it. Even with the history of early deaths of men in my family and my mother's survival of colon cancer, my parents are both healthy and active.

As I write this, they are on a trip to Vietnam and have not shown any indication of slowing down their lifestyle. It is hard for me to imagine my parents unable to care for themselves. I consider the time when I might need to care for them to be a long way off. But there is no way of knowing for sure when the time might come or which of us children will take on the primary responsibility. Similar to Pamela Brubaker's story, all three of us have moved away from home. I would guess that most people, no matter what age, are surprised and bewildered to discover that their parents are in need of this kind of care.

We have received several requests for an issue on caregiving for aging parents, and this may be a topic that will personally affect more of us than any other. As Pamela Brubaker and Karin Gingerich

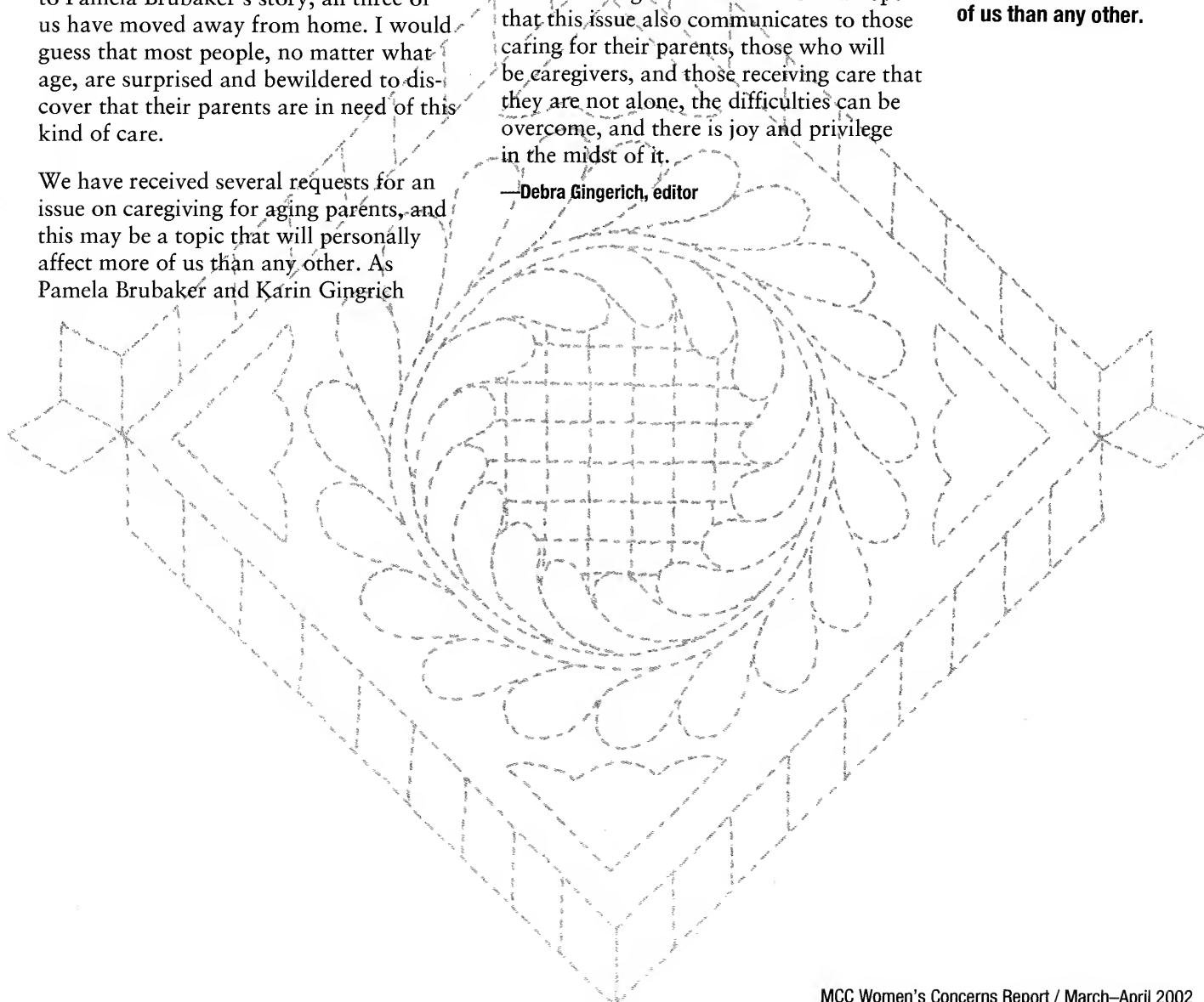
Weaver both indicate in their compilers' comments, most of us will be either caregivers or care-receivers at some time in our lives. The U.S. Administration on Aging states that 95% of the aged who receive paid or unpaid assistance have family members involved in their care.

Caregivers provide an average of 20 hours each week in care. Caregivers experience depression at three times the rate of others in their own age group, and they are more likely to become physically ill. Though this form of caregiving may be one of the most important roles that we undertake, it is not easy and most of us are unprepared. The articles in this issue of *Report* demonstrate that the caregiving process is laced with grief and hard work. I hope that this issue also communicates to those caring for their parents, those who will be caregivers, and those receiving care that they are not alone, the difficulties can be overcome, and there is joy and privilege in the midst of it.

—Debra Gingerich, editor

FROM THE *editor*

We have received several requests for an issue on caregiving for aging parents, and this may be a topic that will personally affect more of us than any other.



The dreams and nightmares of caregiving

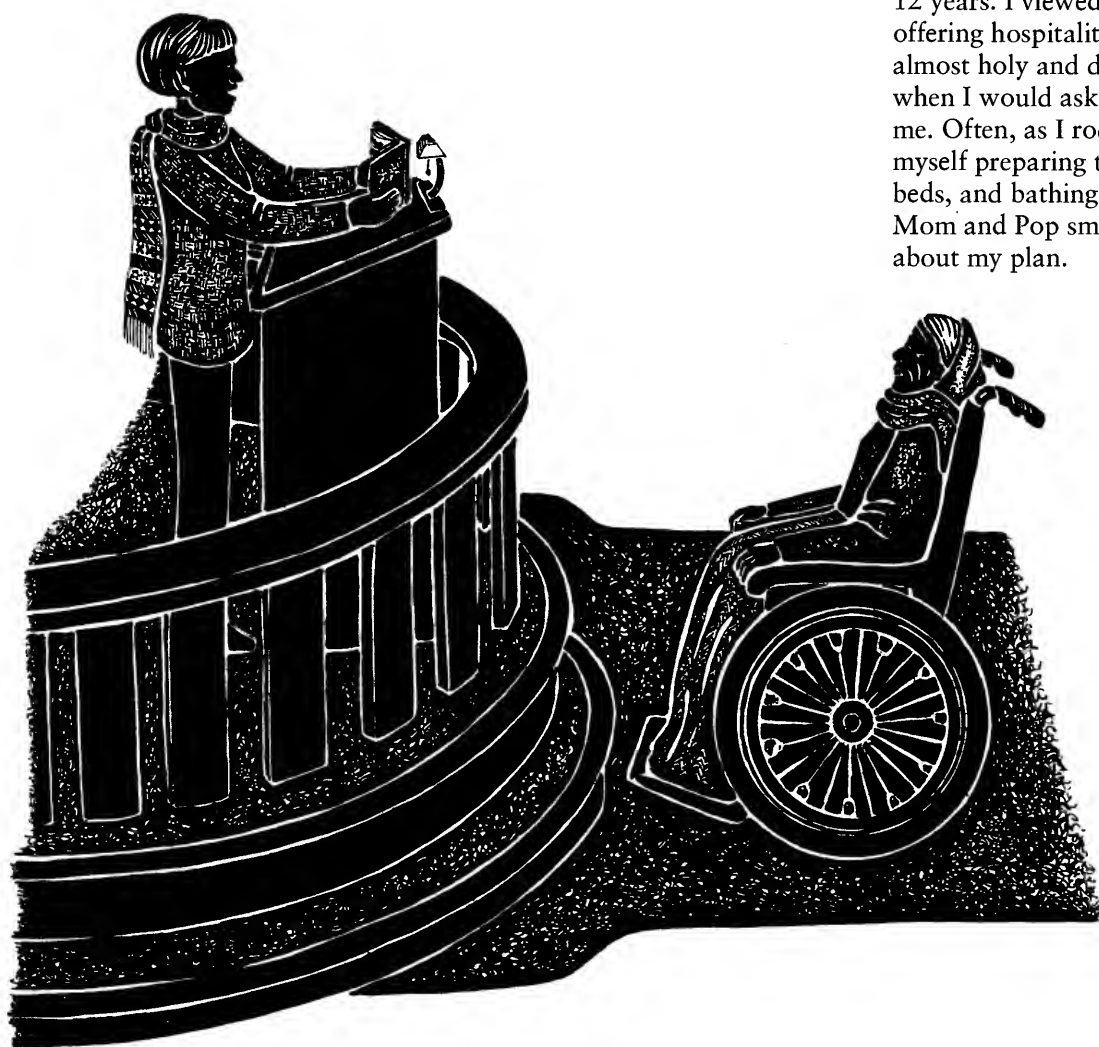
by Virginia Jantzi Hartman

Virginia Jantzi Hartman has lived in Elida, Ohio for the past 30 years. She is married to Dwight and has two adult children. Virginia attends Pike Mennonite Church where she serves as Health Ministry Coordinator. She is on leave from a 30 year career in nursing to be a full-time caregiver for her mother. She creates space for herself by reading, walking and watching birds. Virginia is the sister to Sharon Kraybill who also contributed to this issue.

On a cold, snowy Monday morning my 89-year-old mother was lamenting the fact that the hard winter and her asthma had kept her from church for six consecutive Sundays. Mom had been living with my husband and me for five years, and we usually took her to religious services twice a month. As I listened to her lament, I leaned close and shared my brainstorm, "We are going to church." I gave her a puff from her inhaler, dressed her in insulated clothing, and assisted her to the car. By the time we arrived at the church, Mom's asthmatic wheezing was pronounced, but the parking lot was empty and no one would question my sanity.

As I wheeled Mom into the foyer, I warmly shook her hand, welcomed her to the worship service, and greeted imaginary parishioners. In the sanctuary we sang, read scripture, offered prayer requests, passed the collection plate, and each preached a sermon. As we left an hour later, Mom said it was the best service she had ever attended. It was the ultimate experience for me as a caregiver, and I reflected on how I had become one.

When I was 10 years of age, my parents invited my maternal grandmother to live with us. I watched as my father built a new addition onto our old farmhouse that became "Grandma's room" for the next 12 years. I viewed this introduction to offering hospitality to an aging parent as almost holy and dreamed about the day when I would ask my parents to live with me. Often, as I rode bike, I visualized myself preparing their food, making their beds, and bathing their wrinkled bodies. Mom and Pop smiled as I chattered freely about my plan.



Those dreams became reality as, at age 39, I watched my father help my husband Dwight build an addition onto our house. Our children Tim and Tina called it "Grandma and Grandpa's apartment." Dwight's willingness to construct the apartment was crucial in this process.

For 10 years after the apartment was constructed, Mom and Pop drove from Michigan to Ohio, staying from four to six weeks each visit. During those years they developed friendships in our community and bonded with us as a family. Our situation seemed ideal.

Then six years ago, I woke up to the realization that Mom and Pop were living in their apartment full-time, and I was now both daughter and caregiver. Suddenly those childhood dreams turned into nightmares. Two months after hernia surgery and major complications, Pop died on the bathroom floor of a McDonald's restaurant. Eight months later, Mom sustained a stroke that left her with dementia and temporary loss of movement on one side of her body.

Fear roared in my mind like a siren. I felt prepared for the nursing demands; it was my vulnerability that scared me. I wondered if I would survive. My brain ached with the details of care. It was like treading water 24 hours a day. Mom's frequent calls for assistance wove like a cord around my husband and me as we lost control over our own home.

I felt angry and tried to keep that anger from piercing my dreams, yet I longed for a normal day. I resented that others were free to make unhurried trips to the supermarket and spontaneous visits to their children. I was saddened that congregational ministry to the elderly centered around those in nursing homes and rarely included visits to the elderly and their caregivers who were in family settings. I craved nurturing, compassion, and rest. My focus narrowed. I became an expert giver and a poor receiver.

With my siblings living in different states, the load seemed unbalanced and lonely. I struggled to keep the cost of home care less than institutional care and worried about finances.

We've intentionally worked at open relationships through family conferences, phone calls, and shared respite times. My brother Marvin, who worked beside our parents during their independent days, executes monies and shares power of attorney with me. My brother Vernon offers relational perspective and maintains humor, while my sister Sharon listens to my laments and shares her seminary learnings with me. They all urge me not to lose myself in caregiving problems.

When I took Mom to church that wintry Monday, I received the benefits of my own creativity and humor. I ceased trying to be a perfect caregiver and hired assistants, utilized state-funded respite personnel and placed Mom's name on a nursing home waiting list in case Dwight and I want to pursue other dreams.

Presently, I savor moments of happiness like watching Mom do a belly laugh or making faces at her from the kitchen. I am learning how to meditate while I wait for her to move from her wheelchair to bed. I call her "Rosie Posey," and she calls me "Ginny Winny." It lightens us up. I am discovering my genuine self, taking note of simple things, and accepting my own humanity.

My childhood dreams still linger with me even though they are clouded by nightmares of dementia and grief. As an adult, I have wondered if those dreams were God's call to care for my parents or my need to please them. I have come to view my caregiving as a mixture of the two, and that is freeing for me. ♦

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I am discovering my genuine self, taking note of simple things, and accepting my own humanity.

Sorrow and love flow mingled down

by Carol J. Farran

Carol J. Farran holds the Nurses Alumni Association Chair in Health and the Aging Process at the Rush University College of Nursing, Chicago, Illinois. She has also had family experiences with dementia, as her mother was diagnosed with Alzheimer's disease and her father was her caretaker. She and her husband attend Taize services at the Ascension Parish in Oak Park, Illinois. Their first grandchild was born this past year.

As I reviewed caregivers' comments I found myself saying there is more here than just stress, distress and burden.

I have worked as a nurse researcher with family caregivers of persons with dementia for the past 16 years. The majority of this work has focused primarily on the stress, distress and burden of providing care for family members. With the first study I did in the late 1980s, my colleagues and I made a fortuitous decision to include some open-ended questions in this research study: What are the most difficult aspects about caring for your relative? What are the most pleasant aspects of caregiving? What changes do you most regret? What keeps you going or gives you hope? What do you need most to continue providing care for your relative? What are the good things in your life? (Farran, et al., 1991).

As I reviewed caregivers' responses to these questions, I found that on one hand they were talking about loss, grief, and their feelings of stress and burden, but on the other hand I began seeing comments that suggested something else was also taking place. I struggled to find a way to give a broader perspective to what I was hearing. As I reviewed caregivers' comments, I found myself saying there is more here than just stress, distress and burden. I had a number of personal and professional experiences that helped me to pull this work together in a somewhat different and meaningful way.

The first happened during a Maundy Thursday service as we were singing "When I Survey the Wondrous Cross." The third verse begins with "See, from his head, his hands, his feet, sorrow and love flow mingled down." After the service, I told my husband, "This is it! This is what I am hearing family caregivers talk about—a combination of sorrow and love." About the same time, a chaplain friend suggested that I read Dorothe Soelle's book called *Suffering* (1975). I had also just heard Viktor Frankl speak and was rereading his book, *Man's Search*

for Meaning (1963) as well as some of his professional writings. Both Soelle and Frankl's work on suffering and finding meaning were very instrumental in helping me frame what I was hearing from family caregivers.

First, their work helped me to realize that the feelings of loss, powerlessness, and suffering played a big part in the process of caring for a family member with dementia. Caregivers' comments such as, "He will never be the same person I married" or "You feel as though you lose them over and over again" gave voice to their feelings of loss. Soelle's work on stages of suffering was also particularly helpful. She suggests that as persons suffer, they may be "mute" and unable to express their deepest feelings. She goes on to suggest that lamenting can be a helpful part of the process of moving beyond or gaining solidarity with the event or experience that is causing one's suffering. The whole notion of lament in a clinical research setting gave me a new perspective on why caregivers looked forward to our 1½–2 hour interviews. These interviews gave them a chance to lament what was happening to them in the presence of an interested listener.

Second, this work helped me to understand the close relationship that can exist between suffering and finding meaning. Finding meaning through suffering is a process of "making sense of" or "taking a different perspective about" what is happening in one's life. Frankl suggests that finding meaning involves both a choice and a responsibility. One can choose or not choose to make sense of a particular experience. Choosing not to make sense of this difficult experience may have some detrimental effects for the caregiver—feelings of hopelessness, depressive symptoms, and/or changes in one's mental or physical health. One wife-caregiver was clear about the choice she made, "I choose to make this a

humorous heartache.” Frankl also suggests that finding meaning doesn’t answer the question of “why?” but “what can I make out of this?” Another wife-caregiver expressed it this way, “I never asked ‘why me?’ But rather, ‘why not me?’”

How then might this process take place? Frankl suggests that one’s past experiences, the values one holds, and one’s spiritual perspectives can all shape this process. I found that caregivers talked about a combination of the relationship they had with their family member before they developed dementia, and how they continue to find meaning through the experience of providing care. Caregivers often share that doing the little things and doing things the care-receiver still enjoys are ways in which they make sense out of this experience on a daily basis. One African American daughter caregiver talked about planning a special celebration for her parents’ 50th wedding anniversary. She brought home three dresses and had her mother pick one of them. She said, “When she picked out the same dress two days in a row, I knew this was the right one.” Her mother picked out a white and gold gown and the daughter rented a matching tuxedo for her father. She said, “It was like a Cinderella story. They had a good time and when it was time to go home my mother said, ‘I can’t go before all my guests go home.’”

As proposed by Frankl, my experiences, particularly with African American caregivers, suggest that they often share their spiritual beliefs as they describe their experiences with caregiving. One African American wife caregiver said, “God put me here for a purpose. We are traveling on a highway. Sometimes you get disoriented and lost. You may ask the policemen and you will get back on the highway. You get lost if you don’t pay attention. It’s a quiet voice you have to listen to . . . it’s not a big thunder. If you hear this whisper you can get through” (Farran, Graham, Loukissa, 2000).

It is important to note that finding meaning is not a glamorous, quick, or easy process but involves a combination of time, effort, and chance. And sometimes, while one is in the midst of this process it may be difficult to find the meaning that a particular experience holds. For some persons, it may only

be in retrospect and after their family member has died that their sorrow and love combine to create something new. ♦

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Caregivers often share that doing the little things and doing things the care-receiver still enjoys are ways in which they make sense out of this experience on a daily basis.



To Mom

by Sharon Jantzi Kraybill

Sharon lives in Lancaster, Pennsylvania and attends East Chestnut Street Mennonite Church. She and her husband Herb have two adult children. She recently graduated from Eastern Baptist Seminary in Philadelphia. She enjoys well-crafted words, talking about books with others and canoeing/backpacking with family.

Morning confusion and evening prayers
bookend your days.

You've come for a month again this
summer
along with Gin's simple instructions:
"Cut her facial hair every other day."
"Put her hearing aid in that little
china dish."
"Make sure she washes behind her ears."
"Enjoy her because taking care of her is
such hard work."

You wake up asking me, "Who are your
parents?"
but after Postum and Cheerios you know
who is who and what it what.
My morning kitchen rituals soothe you;
clothes flapping on backyard lines say
all is well.
Your waiting walker holds you in
this space.

Leaving Ohio routines behind unsettles
you,
but we've brought along your pink electric
recliner;
it's your home place in our Pennsylvania
rooms.
You tilt back for the day and sew, snooze,
sew, snooze.
You pin blue bias tape around your 300th
plus baby quilt;
I keep three threaded needles stuck in your
chair's left arm.

When I retreat for too long to
my study,
your handy brass bell's insistent
clanging
brings me downstairs to your
world again.
Unimpressed with time spent
on the computer,
you don't consider looking at
a screen real work.
Napping after lunch earns me
more respect.

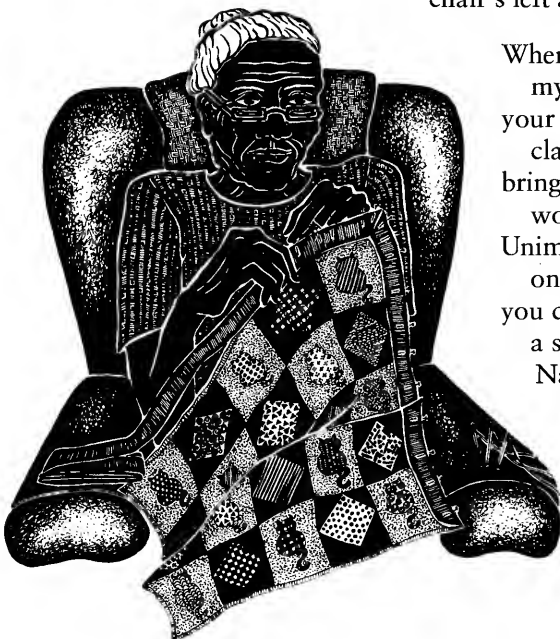
When I was a little girl, if I shivered,
you would tell me to put on my
pink sweater.
Now with this July dripping off my nose,
I cool down by giving you an extra bath.
You reason, "Well, I guess I took care
of you,
and now it's your turn to take care
of me."

Caring for you can be such hard work
that I must now admit to knowing
why some people punch their parents.
I almost tell you that my sanity is
directly linked to your not calling me,
frightened, six times again tonight.

We four always thought of Pop as the
jokester,
but now your quick humor broadsides us.
We ask you how you are. "I'm pretty
good,
but I'm not pretty and I'm not good,"
you grin.
You giggle at you telling the 75-year-old
story of
Nelson Marble mistakenly cooking
buckets of rice.

Like a psalmist you cycle from shrill
noontime lament—
"I lost my home, my car, and my
husband"
through dusk's sweet thanksgivings—
"Thank you for all you do for me,
Sharon"
to the end of your bedtime confessions—
"I pray this all in the name of my Lord
and my Savior."

Now that you are more about being
than doing,
I can see so clearly what you've always
been.
In your new quiet I hear the strong sounds
that all your years have held you in this
faith.
And when you pray the Lord's prayer
each night,
I think I hear heaven and earth stand
still to listen. ♦



Traces of fading patterns

by Bonnie Stutzman

Bonnie Stutzman is a part-time seminary student at Eastern Mennonite Seminary and a part-time hospital chaplain at Rockingham Memorial Hospital in Harrisonburg, Virginia. She is the mother of three adult children and the wife of Ervin.

Mother, Mother," I spoke softly as I bent over and pressed my cheek next to hers. "This is your daughter." There was no response—not that I expected one. I folded back the crisp white sheets to find her hand. "Mother, your hands are cold," I fussed. My family was united in a campaign to keep Mother warm. After all, there were so few ways to express our love. I suspect that this goal of keeping Mother warm had taken on a disproportionate meaning as we white-knuckle grasped at ways to communicate. I cradled her hand in mine. With caressing strokes I massaged her arm. "Wouldn't you love to be home piecing quilts? I still have three boxes of remnants from all the quilts you made for us. Maybe we could make a scrap quilt together."

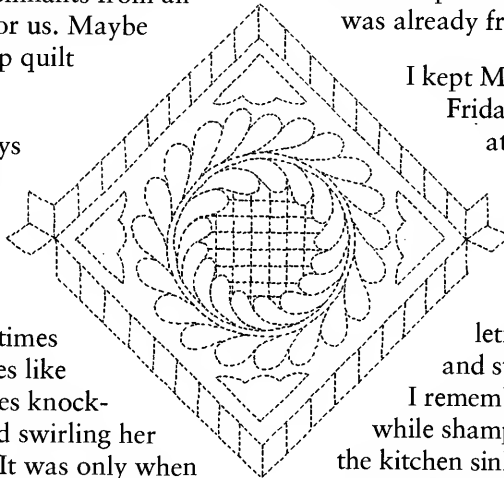
Mother was not always this way. She was not always a resident of a nursing home. Signs of dementia came over her like waves on the sea—at times like ripples, other times like violent pounding waves knocking her off her feet and swirling her into murky darkness. It was only when we looked backwards over time that we could gain a perspective of the scouring away of the very rock-bed of Mother.

At first we didn't understand what was happening to Mother. She would complain of hearing voices or seeing bright lights. She would talk of burglars. She struggled to make decisions. Mother would blame Dad for not wanting to spend money, complain that the weather was not right, or mention that it was the wrong time of the day. No amount of reasoning could reach her. It was getting harder to trace the patterns of her thoughts.

We noticed changes in her driving. Mother struggled to park the car between the white lines. Instead she was pulling onto the grass. She complained of tiredness. She became obsessed with thoughts that

we were plotting against her. I remember one summer evening when the extended family was having a cook-out on the family farm. While standing with Dad on the bridge overlooking the farm pond, Dad informed us that it was not expedient to talk about Mother's changes with her. She would become quite belligerent and make life miserable for Dad.

Within that first year, Mother was given a mental-status evaluation at a psychiatric hospital. The doctor confirmed that she had a slow progressively deteriorating brain disease. It was time for us six adult children to get into action and share the care and supervision of Mother. Dad was already fraying with burnout.



I kept Mother for 12 hours each Friday while Dad worked at the Auto Auction.

I would divide the day into three four-hour segments and simply repeated the activities of eating, toileting, resting, walking, and structured activity.

I remember struggling with her while shampooing her long hair in the kitchen sink. Mother would "forget" to bend over the sink, soap would fly everywhere, and water would soak her dress. The whirring of the hair dryer, the ringing of the telephone, my children's noises from play all became threats to Mother's security.

Mother would "forget" how to lay down on the sofa for a nap. Door knobs became a mystery. I would find her standing before a closed door, fumbling at the door hinges, wanting to go outside. Mother was intrigued with the sensory stimulation of buttons, hems and zippers. She was constantly fingering her clothes. She was regularly pulling out her hair pins. What would we do with her beautiful hair that Dad struggled to pin into a neat bun at the nape of her neck? Should we cut her hair or braid it into

It was only when we looked backwards over time that we could gain a perspective of the scouring away of the very rock-bed of Mother.

In all this I had needed to ease away from the unrealistic goal that I could ever repay the huge debt of love I owed to my parents.

a pony tail? Watching these deteriorating changes in Mother was like attending a funeral that would never end.

I soon found myself resentful that Mother was with me for such a long day. I wondered who was the true victim of the disease: my mother or the family. I prayed against the disease. I sobbed in my Dad's embrace, feeling angry at this graceless disease. After all, they had been godly parents, successful farmers, and deacons in the church for the past 35 years. They did not deserve this!

In the third year of Mother's care, she stumbled and cracked her pelvis. Mother needed physical therapy. She was admitted to full-time nursing care. The family was stunned. Had it really come to this? Were we unable to protect our fragile, vulnerable Mother from the threats of everyday living? Yet I could hear a collective sigh of relief from my siblings. We were all feeling the squeeze of "compassion fatigue"—caring for mother while also caring for our families.

In all this I had needed to ease away from the unrealistic goal that I could ever repay the huge debt of love I owed to my parents. It was time to set up a new rhythm of care and support. Dad would eat dinner with my family each week and then we would visit Mother at the nursing home together. Because I had recently enrolled in a degree completion program at a local college, I could set aside blocks of time for study.

It has been seven years since Mother was admitted to Mount Hope Nursing Home. I grieve over the fact that the recent memories of Mother are all the same: she is lying in bed, covered by a patchwork quilt she once made, and unresponsive. The distinctive patterns of life that make Mother unique are bleached from her memory. How can I again reach this wonderful woman who lovingly stitched quilts for her family? We have become her memory holders. We are the ones who lovingly identify the fading traces of who she once was.

Ruth Haldeman died Thursday, September 13, 2001, one week after this article was written. ♦

Caring for aging parents: What does the Bible say?

by Elizabeth G. Nissley

Elizabeth (Libby) G. Nissley, mother of four adult children, lives in Mount Joy, Pennsylvania with her husband Ken. She works as a clinical nurse specialist, outpatient therapist at Philhaven and is completing her final year of seminary studies. She is looking forward to future ministry possibilities.

Honor your father and mother, as the LORD your God commanded you, so that your days may be long and that it may go well with you in the land that the LORD your God is giving you (Deuteronomy 5:16). We find this commandment of God, along with all of the others of the Decalogue, often disregarded in the family and generational conflict recorded in scripture. But Paul, in his instructions to the Christian household (Ephesians 5), holds to the concept of honor for parents and notes that it is the first commandment with a promise, one that continues to be binding on those who follow Jesus.

Although "honoring" was a common theme in the Bible, we do not talk much about "honor" in our present North American context. The word "respect" may be a more accessible term. Respect does not mean just being civil, polite, or obligatory with visits and celebrations. It is not returning kindness for good received. Respect means honoring and valuing another—the parent, the elder—for who they are, one created in the image of God and one whom God loves. Respect is mandated even though divine grace may seem to be lacking within the other.

Honoring/having respect for parents is only one aspect of parent/child relationships. Paul asks fathers (and mothers) to

teach their children the ways of the Lord and to guide and discipline without “provoking to anger.” Images of God as a loving parent who takes care of, protects, nurtures, looks out for, and gives blessings and good gifts to the children provide a scriptural model for a kind of parenting that invites reciprocal blessing and honor. There is great joy in giving and receiving such blessing from parent to child and child to parent.

Not everyone has a goodly heritage (Psalm 16); most of us have both joyful and painful memories and/or present experiences. Converting a “painful inheritance” into something good, into a respectful relationship, requires, not undoing or forgetting, but ongoing transformation! To honor unworthy parents is an act of grace. Whether the relationships have been good or difficult, the need for grace and transformation intensifies when parents and children are required to communicate, make decisions, and provide care because parents are no longer able to function independently.

Forgiveness and healing may need to take place so that an adult child can be available to an aging parent or one who needs care. Jesus modeled forgiveness in his teaching prayer in Luke 11 (“Forgive us our sins as we forgive those who sin against us”) and in his own prayer of forgiveness for those who killed him. Such forgiveness is a gift of the Holy Spirit, but it also comes as persons make deliberate choices to follow Ephesians 4:31–32, “Put away from you all bitterness and wrath and anger and wrangling and slander, together with all malice, and be kind to one another, tenderhearted, forgiving one another, as God in Christ has forgiven you.”

None of this can be done in isolation. Sometimes siblings or the extended family need to experience healing so that the burden can be shared. Psalm 133:1 notes, “How very good and pleasant it is when kindred live together in unity.” Working towards such unity and agreement requires divine grace.

Within our communities of faith, we have traditionally supported each other through life transitions. We believe that the Church, as it exercises a variety of spiritual gifts, is an expression of the body of Christ on earth. We understand that the gifts are to be used for the building up of the entire body. We know that we are to “bear one another’s burdens” (Galatians 6:2), and in doing so we will fulfill the law of Christ. This requires acknowledging need, asking for help, and listening to the discernment and counsel of caring Christian sisters and brothers. It may mean relinquishing control, seeking professional counsel, and welcoming alternative caregivers.

Friends need to listen, rejoice, and weep with those who are experiencing the ups and downs of caregiving. Providing care for aging parents often tests not only the

Whether the relationships have been good or difficult, the need for grace and transformation intensifies when parents and children are required to communicate, make decisions and provide care because parents are no longer able to function independently.



The scriptures teach God's people how to cry out distress and impossibility (read the Psalms!) and also give many promises of help, of God's presence, wisdom, peace and protection.

parent/child relationship but can also bring stress into other relationships. Respectfully balancing the needs of elders while working, relating to a partner, children and friends, and taking care of oneself may seem beyond possibility.

The scriptures teach God's people how to cry out distress and impossibility (read the Psalms!) and also give many promises of help, of God's presence, wisdom, peace and protection. Caregivers may struggle to maintain their own faith and hope. Verses of encouragement, "Who will separate us from the love of Christ?" (Romans 8), "The Lord is my helper," (Hebrews

13), and "Even if my father and mother abandon me, the Lord will hold me close" (Psalm 27:10) are just a few of the assurances of God's love to children who are experiencing the joys and the difficulties of caring for their aging parents.

Caring for aging parents is not done primarily to obtain a blessing or the promises of God. Honoring parents in all kinds of situations ultimately brings well-being. The responsibility is only fulfilled with grace, forgiveness, and the support of the faith community. ♦

Taking a vacation while caring for Mom

by Raquel Trinidad and Rolando Santiago

Raquel Trinidad and Rolando Santiago are married and the parents of two teenagers. They live outside of Washington, D.C. Raquel is a registered nurse and currently serves as an intravenous nurse. Rolando has a Ph.D. in educational psychology and statistics. He currently serves as a public health analyst in the U.S. Department of Health and Human Services. They are active members of Hyattsville Mennonite Church.

I visited Doña Modesta in her room several times a day, telling her I loved her, kissing her on her forehead, and making conversation.

Raquel called her sister-in-law María several times in the spring of 2001 to ask whether she would care for Doña Modesta at her home while our family took an August vacation in Puerto Rico. Each time María said she could not do it. Raquel then suggested that I go to Puerto Rico with our teenage children, Jared and Karla. She would stay behind at home caring for her mom in Silver Spring, Maryland.

Doña Modesta was now bedridden. Arthritis had almost fused her knees, so Raquel would gently bend her legs several times a day. Over the spring and summer months, Doña Modesta's upper-body muscles got weaker and weaker. The bones in her right shoulder were brittle from osteoarthritis. It hurt each time she put pressure on them. She had difficulty sitting up to eat. Later on, she even had difficulty lifting and stretching her right arm. This made it hard to reach the spoon and fork to feed herself. Sometimes we sat her on a chair in the family room to give her a different view from the one in her bedroom. But then we had to watch her

carefully because her body would slide down the chair after a few minutes. The extent of Doña Modesta's speech was to let us know whether she was hungry, thirsty, or had some other need. She could hardly remember events in the immediate or distant past. Sometimes Doña Modesta called us two or three times from her room during the night. She wanted to know where we were.

I visited Doña Modesta in her room several times a day, telling her I loved her, kissing her on her forehead, and making conversation. She loved to play verbal word games. For instance, I would tell her in Spanish that she was "bella" (or beautiful), and she would answer, "como una camella" (like a camel). Jared and Karla also visited her often. Sometimes they brought her something to drink, other times they answered her calls, especially when Raquel and I were not in sight.

Five weeks before vacation time, we received a call from María telling us that she was willing to care for Doña Modesta. The news thrilled us. We immediately purchased plane tickets. Then, one week before our August 3rd departure date, we made the seven-hour trip to the small village of Woodridge, New York, at the foothills of the Catskill Mountains, where Modesto and María Cruz live.

Upon arrival, Raquel thoroughly briefed María on how to care for Doña Modesta. She carefully explained the daily schedule for administering medications for congestive heart failure, asthma, high blood pressure, hypothyroidism, and chronic arthritis pain. She told María that Doña Modesta's adult diapers would have to be changed about three times a day. Raquel also explained how Doña Modesta needed to be turned several times a day into different positions so that she would not lay on any one body part for a prolonged period of time. She also needed to sit in a chair on occasion. Otherwise, Doña Modesta could develop sores on her body. Raquel provided creams and lotions to rub Doña Modesta's frail skin. Someone would have to spoon feed her mom three times a day and give her a protein rich vanilla flavored drink at each meal time or whenever she requested a drink.

Four days after our family arrived in Puerto Rico, we received a call from María. Doña Modesta had been hospitalized due to dehydration. María explained that Doña Modesta had refused to eat or drink. Hospital staff began to feed her intravenously. The shocking recommendation came from the attending physician that her left leg should be amputated because of gangrene on her heel and alongside her leg. Raquel immediately called from Puerto Rico and spoke with a fellow nurse at the hospital in Monticello, New York, and ordered hospital staff not to

amputate. Doña Modesta was not in a condition to withstand such severe intervention. Raquel considered returning back to the continental United States to be with her mom, but after a few days, Doña Modesta was released and sent back to María and Modesto's home relatively well.

Our family returned from vacation on August 21st. We drove Doña Modesta back to our home on September 2nd. On the 4th, Doña Modesta's physician hospitalized her to hydrate her and to tend to her gangrene ulcers. Doña Modesta spent about a week at the hospital, but this was the last time she ever visited there.

Doña Modesta died peacefully at home on Friday, November 23rd, the day after Thanksgiving, surrounded by Raquel, Jared, Karla, myself, and my parents, Fidel and Patricia Santiago. Raquel says she cared for her mother unconditionally over the last four years because this is exactly what her mom would have done for her. ♦

She carefully explained the daily schedule for administering medications for congestive heart failure, asthma, high blood pressure, hypothyroidism, and chronic arthritis pain.



Caring for my dying mother

by Anne Plett

Anne Plett of Landmark, Manitoba has 23 years of experience in working with people suffering from terminal illness and their caregivers. She is Palliative Care Facilitator for the South Eastman Region. She works at Fort Garry Mennonite Fellowship.

Caring for a dying person at home is one of the most significant and meaningful, as well as difficult, tasks anyone can undertake.

My mother was diagnosed with multiple myeloma at the end of May, 2001. She died at her home in Clearbrook, British Columbia on July 14th, surrounded by family, either in body or “embodied” by photographs on every wall of her bedroom. This was the context in which we witnessed the transition from life (labored breathing) to death (total silence).

Caring for a dying person at home is one of the most significant and meaningful, as well as difficult, tasks anyone can undertake. The responsibility for making this work ultimately rests with the caregiver and therefore can not be managed by everyone. It is physically and emotionally demanding and requires a great deal of patience. Agendas and time lines are dictated by the person who is ill and the focus is totally on that individual and his or her needs. Therefore, caregivers must

attend to their own well-being to ensure they can continue to function effectively. From my experience, one of the concerns of patients, apart from fear of pain and the unknown, is that their caregivers will “burn out.”

In my mother’s case, I shared the responsibility with my sister and father. Together we managed the personal care, bathing, toileting and symptom control. In the initial stages we tried to involve her in the decision making process so she could exercise control over her own quality of life. How much pain was she willing to live with in order to keep clarity of mind? What tasks did she need to still complete and how much energy did that require? These issues were discussed on an ongoing basis and, at times, it was difficult to separate our perception of her needs from her wishes.

Now, several months later, we look back and speak of this time as difficult and filled with uncertainty and doubt but also tremendously rewarding. We watched our mother move very quickly, yet painfully slowly, from being alive to “living in the shadow of death.” Conversations with her became increasingly difficult because of the strained attempts at communication and the metamorphic nature of her words. We needed to be intuitively aware of her thoughts and the meaning of her behaviors in order to meet her requests and needs. The loving relationship with our mother stood us in good stead, and God gave much wisdom to discern when to “enter in” and when to just be present.



Providing comfort and care in the face of approaching death made us increasingly aware of our own mortality. But God was present in this situation, and we were acutely conscious of the sacredness of the moment and the holy presence that seemed to surround our mother. Even the home-care nurses, who periodically checked in, remarked on how peaceful the room was.

My work as a palliative care nurse has made me aware of the limits of medicine and how difficult it is to take a hard and honest look at death. In the medical world, we tend to see death as failure or the absence of cure. Further, we fear death personally because it has the ability to snatch away all that matters, not only our own life but, frighteningly, the lives of those we love. But having worked in this area for many years and having encountered death on a number of occa-

sions, I've observed and learned a few things. For me, my mother exemplified a "good death," and it is because of these types of experiences that I can move beyond superficiality to living as fully as possible. Cliche or not, through my mother's death, I have come to appreciate life all the more. What makes this possible is recognizing the ever present reality of death, and that awareness demonstrates itself in various ways. As a family we talk about end of life issues, in relation to our hopes and dreams, and I am more cognizant of not leaving things unsaid, mending bridges, and keeping life more simple. To live in the present has, in fact, enabled me to live in the future. As the Psalmist puts it, "So teach us to count our days that we may gain a wise heart." ♦

But God was present in this situation and we were acutely conscious of the sacredness of the moment and the holy presence that seemed to surround out mother.

Women in leadership

Gwen Groff was ordained on November 4, 2001 as pastor of Bethany Mennonite Church, Bridgewater Corners, Vermont. Gwen received her MDiv from Lancaster Theological Seminary in Lancaster, Pennsylvania and is the former director of MCC U.S. Women's Concerns.

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NEWS VERBS

WOMEN'S CONCERNS REPORT

Looking Forward

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in leadership



JULY-AUGUST 2002

Women and AIDS



SEPTEMBER-OCTOBER 2002

Women who have
left the church



NOVEMBER-DECEMBER 2002

An Anabaptist theology
opposing violence
against women

As of the **May-June 2002** issue, the subscription price for *Women's Concerns Report* will increase to \$15U.S./\$18Cdn. for one year and \$25U.S./\$30Cdn. for two years. Subscription fees were first established in 1994 and have not been increased since that time. Thank you for your understanding.

MCC Women's Concerns is on the web. Reach the MCC U.S. Women's Concerns website at <http://www.mcc.org/us/peace-andjustice/women.html>. The website for MCC Canada Women's Concerns is <http://www.mcc.org/canada/women.html>. Also, MCC British Columbia has a website with resources on domestic violence and sexual abuse at <http://www.mccbc.com/abuse/>.

To find information on how women's groups are encouraging peace, check the website <http://www.peacewomen.org/>. **PeaceWomen.org** seeks to nurture communication among a diversity of women's organizations by providing an accessible and accurate information exchange between peace women around the world and the UN system.

The MCC U.S. Washington Office is supporting the ratification of the **United Nations Convention on the Elimination of All Forms of Discrimination Against Women (CEDAW)**. Adopted by the UN General Assembly in 1979, CEDAW provides a universal definition of discrimination against women. Nations adopting CEDAW agree to take all appropriate measures, including legislation, to end this discrimination. President Carter signed the treaty in 1980, and fifteen years later at the UN Conference of Women in Beijing, the United States made a public commitment to ratify CEDAW by the year 2000. This has not yet been done.